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Addressing the Spiritual Needs of People Aging with Dementia and/or Lifelong Disabilities

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Case Study

Addressing the Spiritual Needs of People Aging with Dementia and/or Lifelong Disabilities

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Educational Objectives

1. Present the need for spiritual care as part of holistic care for people living with dementia and/or lifelong disabilities.
2. Distinguish the difference between spirituality and religion.
3. Discuss how to assess the spiritual needs of people living with dementia and/or lifelong disabilities.
4. Show through case study examples specific ways to address the spiritual needs of people living with dementia and/or lifelong disabilities.

Introduction

Just as caring for the physical and emotional needs of people aging with dementia and lifelong disabilities is essential for their well-being,

so is providing spiritual care. Yet often this component of holistic care is neglected.

“Indeed, in today’s care system, the physical needs of patients are obviously recognized; that after all is why they are in the system. If the right personnel are available, and if time permits, a patient’s psychosocial needs can also be addressed. But all too often their spiritual needs are not recognized or considered legitimate targets for intervention; certainly these needs are not frequently acknowledged, recognized and dealt with by medical professionals” (Sapp, 1999).

A visit to a new doctor’s office usually begins with questions about medical status, past and present. Similarly, a visit to a new psychiatrist or social worker begins with questions about mental and social health and history. Spiritual health and well-being are rarely, if ever, assessed. Such an assessment can provide valuable insight into a person’s total health or disease. Yet, rarely is more spiritual/religious information gleaned by those caring for elders than someone’s faith affiliation and perhaps place of

worship; that is, scratching the surface.

According to the 2014 Pew Research Center Religious Landscape Study, about 72 % of people over 75 consider their faith to be very important to them. The Alzheimer’s Association’s 2017 *Alzheimer’s Disease Facts and Figures Report* states that one-third of people over 85 have Alzheimer’s disease, and nearly one half have some form of dementia. So, at a time when they may need their faith to help them cope with dementia and other major life transitions, elders are often unable to initiate and sustain faith practices and spiritual disciplines that bring them peace, comfort, a feeling of closeness to God. This is also true for people aging with lifelong disabilities, who may not have the physical, cognitive, or communication abilities to initiate, ask for or sustain faith practices essential to their well-being. Family and professional caregivers often do not assess spiritual needs or assist with vital religious and spiritual practices which could enhance quality of life for those they’re caring for.

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The Federal Government mandates that skilled nursing facilities must promote each resident's quality of life (42 CFR §483.15). Yet, spiritual/religious care in long term, assisted living, and nursing care facilities is often relegated to volunteers who provide generic worship services, religious music programs, or friendly visits. While these programs might be quite valuable, they do not address the unique spiritual needs of everyone and cannot meet the challenging needs of residents for day-to-day spiritual support through life's transitions.

If 72% of elders over 75 consider their religious faith to be important, then facilities are not doing enough to maintain or enhance elders' quality of life. This is especially true in regard to residents who, due to dementia or lifelong disabilities, cannot practice their religion and nurture their spirit without assistance. Administrators, doctors, nurses, social workers, recreational therapists and all staff, not just chaplains, should seek to understand and address the spirituality of residents. Most facilities caring for elders do not have chaplains on staff, so this needs to be a part of everyone's responsibilities.

Spirituality and Religion

Although there is no single, broadly accepted definition of spirituality, many agree that it involves the search for meaning to life. Spirituality, in contrast to religion, pertains to a sense of relatedness to nature, all humanity, and the Transcendent. Although it need not be the case, spirituality is often contextualized within a religious tradition, a specific system of belief, worship, and

conduct (Post and Whitehouse, 1999). Fischer, in her book *Winter Grace* (1998), says that spirituality doesn't mean just one compartment of life, but the deepest dimension of all of life; spiritual life is not a static state but movement, growth, and process.

Comparing spirituality to religion on its website, www.reComparison.com says: "*Spirituality is about finding one's own path, which may require the assistance of religious practices or spiritual leaders, but which can also be achieved alone or through unconventional means. Spirituality is more about an inner quest than an outward performance, so it can be harder to recognize and it can also be much more individual than religion. People may achieve spirituality in their own unique way. Some people have found a spiritual connection through prayer or meditation, while others were struck by spirituality while walking, surfing, gardening or even working. Typically, spirituality involves feeling a connection to a higher power or to a larger reality, or finding a deeper understanding of one's own nature. An individual may spend a lot of time thinking about spirituality, but without being part of a particular religion.*"

Emile Durkheim (1912) maintained that religion involves a unified system of beliefs and practices relative to sacred things. This then evolves into a moral community called a church (community of faith.) The defining characteristic of a religion is that it is an organized form of belief, www.reComparison.com suggests. "*Someone who is part of a particular religion will usually*

join in with organized activities or rituals, and they will probably follow the teachings or philosophies either of a living spiritual leader or of an important religious figure such as Jesus, Moses or Buddha. Religion is, therefore, often based on the past, while spirituality tends to be more about individual development in the present."

Sam Harris, neuroscientist, philosopher, best-selling author, and self-proclaimed atheist, claims, "Spirituality must be distinguished from religion because people of every faith, and of none, have had the same sorts of spiritual experiences" (2005).

Everyone is a spiritual being, but not everyone adheres to a particular religious belief or becomes part of a religious organization. Whether persons living with dementia and/or a lifelong disability live at home with caregivers or in a facility, finding ways to help them explore and nurture spirituality is essential to providing quality care, as is enabling them to practice their faith, if they've become part of a particular religious group.

Identifying and Addressing Spiritual Needs

Humankind experiences deep needs for security, trust, reassurance, love, inclusion, joy, hope, and acceptance, among others spiritual needs. How each person feels and experiences these is as unique as there are people on the earth. So, spiritual care must be person-centered, uniquely addressing the specific needs of each individual in the specific way he needs them addressed. Conducting a spiritual assessment

can help discern each person's needs. It is important to ask about rather than assume needs. A spiritual assessment should not be done with a clip in hand, but rather over time through conversation and relationship. For someone living with dementia, it is best to conduct an assessment during the early stages. If the person with dementia or a lifelong disability is unable to communicate well, then talk with the person's family or caregivers to discern past and present spiritual and/or religious needs and practices.

A sample Spiritual Assessment Tool from *When Words Fail: Practical Ministry to People with Dementia and their Caregivers* (Berry, 2016) asks:

- What gives you hope?
- What gives you purpose?
- What gives you comfort?
- What helps you feel closest to God and/or most whole? (prayer, meditation, nature, art, service projects, family, friends, faith community involvement, holy scriptures, worship, music, or others)
- What (if any) religious rituals, symbols, and practices are important to you? (prayer, meditation, holy scripture reading, worship, music, icons, candles, scents, or others)

Thibault and Morgan, in *No Act of Love Is Ever Wasted* (2009), assert that, denied the ability to grasp words, persons with dementia (or lifelong disabilities) often relate to symbols that remind them of the presence of God, like the Bible, a cross or crucifix, icons, statues, flowers, sacred pictures, stained glass windows, candles, rosaries, and even the smell of incense; all

speak to the senses of those who have cognitive impairment and cannot comprehend the meaning of words. This is true for persons living with lifelong disabilities, as well.

Depending on the person's level of cognition, further conversations might explore such questions as: What religious or spiritual influences shaped your life? What prevents you from exploring and nurturing her spirit?

When people lose the ability to nurture their spirits and/or practice their faith in ways that give them purpose, comfort, peace, and a sense of community, part of providing holistic care is helping them do those things.

Case Study #1

Emily, an 85-year-old woman with debilitating rheumatoid arthritis, COPD, and dementia, has now been diagnosed with Stage 4 stomach cancer. She's been admitted to hospice in the long term care facility where she lives. A lawyer has her POA, and there is no known family.

Emily's contracted hands and legs hurt, and she often cries in pain. Because she's prone to sliding out of her wheelchair, she can often be found sitting by the nurses' station where they can keep an eye on her. This is often a noisy place, and she gets visibly upset when things get chaotic. Although her speech is predominantly garbled, with some "choice" words she's retained, she routinely rejects caregivers when they need to provide hands-on care. Staff have tried to determine what might improve Emily's quality of

life. They've experimented with music, pet and art therapy, and visiting children, all of whom she also rejects.

The hospice staff has had some luck providing essential care at times, assessing physical needs, providing medication, and soothing baths, but the hospice chaplain has been unable to discern her spiritual needs. All anyone knows about Emily's faith background is her church's name, listed in the chart. However, since she has lived in the facility for 10 years, she's been unable to attend church, and no one can recall a minister visiting in recent years.

One day the facility's social worker decides to try a new tactic. It is a beautiful spring day, so he knocks on the door to Emily's room, where she's sitting in a wheelchair in the semi-dark. When he asks Emily if she would like to go outside, Emily surprisingly looks up and clearly replies, "Yes." Before Emily can change her mind, he wheels her out under the portico and sits on a bench beside her. "Let's not talk," he suggests, "but listen to nature around us." Knowing that Emily was usually sitting near the nurses' station where constant noise bombarded her, the chaplain thought perhaps a quiet break would be nice.

For 30 minutes they sat in silence, soaking up the sun and sounds. Gentle breezes swayed the trees, the sweet scent of flowers wafted through the air, and the laughter of children playing in a nearby schoolyard drifted across the street. Emily seemed mesmerized and did not fall asleep, as the chaplain

assumed she would. When lunchtime arrived, the social worker hesitated to bring up the need to return inside, expecting loud objections. Instead, when he told her, Emily nodded in agreement. As she was wheeled past the nurses' station, people noted the transformation of her usual anxious expression to one of calmness and serenity. They watched her wheel by in amazement.

This was a new beginning for Emily. Being outside, where she was rarely able to go, nurtured her spirit. It transported her to a place of solace and peace. The social worker detailed their initial visit outside into Emily's care plan, and other staff began taking her outside for a walk or to sit, when able. The hospice chaplain and various staff members began having success as they gently tried to assess Emily's spiritual needs and found out other ways to help her tap into her faith. They discovered that scripture reading and hymn singing were important to Emily, too, both things she could not initiate on her own due to dementia and her physical limitations. They began singing old hymns or reading scripture together on sunny days outside or rainy days inside. Emily began to open up. The physical pain was still present, but her ability to cope with it got better. Her physical affect improved as her quality of life was enhanced. She lived more joyfully until her death six months later.

Case Study #2

Born with cerebral palsy, 71-year-old John has lived in a long term care facility since his mother's death 15 years ago. Despite chronic

urinary tract infections, he is reasonably healthy. Although he does not have much controlled use of his arms or legs, he gets along well in his motorized wheelchair.

His speech, however, is almost unintelligible, and because of almost constant movements due to the CP, John cannot use a computer for communication. Instead, he uses a pointer attached to a helmet on his head. With it, he can painstakingly point to letters and spell words on a laminated board which someone must remove from his wheelchair's backpack and set up. Because this type of communication is slow going, others often don't take the time, or energy, needed to listen to him. Communicating with fellow residents is complicated by his disability, as well as theirs.

John is an intelligent man whom others often mistakenly consider to be mentally challenged because of his communication difficulties. Usually kind and with a quiet disposition, John's inability to be understood sometimes leads to angry outbursts. He's immediately ashamed when this happens and apologizes. Lately, however, his frustrations have been building up and something really seems to be bothering him.

He used to attend church with his mother, and sometimes his eldest brother, but he hasn't been in many years since his mother died and his brother moved out-of-state. He enjoys the facility's Sunday worship service, though, and staff often find him sitting silently in the chapel in quiet contemplation. The minister has noticed how John's become increasingly vocal during

the weekly worship service's prayer time, trying to communicate as best as he can. As the minister pulls out John's board and watches his word spelling, John shares numerous prayer requests, spelling them out laboriously as others wait. His requests usually focus on the needs of other residents and staff whom he's obviously been listening to. Everyone is moved by John's obvious concern for them and genuine interest in their wellbeing.

Because the minister has had to limit John's prayer requests to one per service, so that others would also have a chance to share, she has decided to stay after the weekly service and begin spending one-on-one time with John. She's only there part-time each week, for the worship service and a Bible study, but the minister can tell something has been bothering John and wants to discern what it is.

In their new weekly half-hour sessions when she can focus on John, the minister learns of his frustration over not being able to help people and feeling useless. Throughout his life, prior to living in the facility, John did visitation of sick people with his mother and prayed with her over their needs each day. Until now, John says, no one had asked him about his faith or feelings of not having a purpose. He expresses relief over just being able to talk about this.

The minister encourages John to continue getting prayer requests from others, praying for them and assisting her by filling her in each week on the needs of this congregation. John expresses joy over this newfound ministry and purpose.

He spends more time listening to others and sitting quietly at the bedside of people who are sick. Staff begin sharing requests with him, too, and are more intentional about helping him communicate. John seems more happy and fulfilled.

Conclusion

Everyone needs the chance to nurture their spirit, whether through conventional religious practices such as worship, scripture reading, ministry projects, and prayer, or through spiritual disciplines like communing with nature, caring for animals, quiet meditation, or inspirational music. Even with dementia or a lifelong disability, elders need spiritual care unique to themselves which may enhance their quality of life. Everyone involved in their care, family or professional, can and should take an active role in accessing and addressing spiritual needs.

“People gradually lose their cognition” (but) “they do not lose the presence of their creator within them. Although they may no longer be able to articulate their faith, the essence of their faith lives on in their soul which outlives their body and its ability to function” (Swinton, 2012)

“A smile, nod, tear or twinkle in the eye can be revealing,” says Pat Otwell in *Guide to Ministering to Alzheimer’s Patients and Their Families* (2007). “Just because those faith experiences cannot be articulated, it does not mean that they do not, and cannot, occur at every stage of the dementia disease (or lifelong disability). After all, words are inadequate to articulate

“holy moments” that transpire between anyone and God.”

Study Questions

1. How were John’s and Emily’s spiritual needs assessed? How was their quality of life enhanced when spiritual needs were addressed?
2. Why should assessing the spiritual needs of people be a regular part of providing holistic care and what are the benefits?
3. What resources are needed to meet the spiritual needs of people? Are those resources readily available in care facilities or private homes where people with dementia and/or long term disabilities reside? What changes could be implemented to ensure they are available?

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